Publieksvoorlichting over borstkanker en borstzelfonderzoek

English summary

Public education about breast cancer and breast self-examination

In the Netherlands one out of about every 13 women gets breast cancer. Considering its high incidence, breast cancer is not only a medical problem, but increasingly a problem almost everyone in society has to deal with. Considering dealing with breast cancer as a community problem, it is assumed that health education may be an instrument to help "healthy" women to deal with this problem in an adequate way.
This assumption has led to the start of a research project on education about breast cancer and breast self-examination by the Provincial Cross Association of South Holland and the former Study Center for Social Oncology of the Dutch Cancer Society in 1980. The main purpose of this project is briefly described in **chapter one.** Further in this chapter it is stated that a health education approach has been chosen because it is assumed as justifiable to increase people's own possibilities to control their own health. If health education activities are undertaken directed to influencing behavior with respect to health and illness at least four necessary steps should be taken:

1. problem analysis should make clear that there is a health problem that is related to individual behavior;
2. analysis should make clear what the causes and determinants of this specific behavior are;
3. attempts should be tried out to influence the behavior, that is, to motivate people to change their behavior;
4. the effects of these attempts should be evaluated in an adequate way.

After having presented a more specific justification of the reason why this health subject (breast cancer) was chosen the two main questions dealt with in this study are formulated.

1. Which behavioral determinants play a direct or indirect role in explaining information seeking behavior with reference to breast cancer and performing breast self-examination among "healthy" adult women?
2. What are the effects of health education interventions with reference to breast cancer and breast self-examination at these types of behavior and its determinants?
   Finally in this chapter an overview of the structure of this study is presented.

In **chapter 2** (Problem analysis: an overview of literature) an overview is presented of frequent occuring problems in cancer education in general and education about breast cancer and breast self-examination in specific. It is stated that there still often exists a taboo on cancer: a disease one avoids to talk about, a disease that is often associated with dying, serious suffering etc. There are still many misconceptions about cancer, not only among the public but also among for example general practitioners and nurses. Specifically these care givers however should play an important role in educating the public about cancer.

The question whether one should educate people about breast self-examination in order to stimulate them to perform the behavior in an adequate way, depends on the value of breast self-examination as a method to detect breast cancer at an early stage. In literature there is no unanimity about its value in this respect.
One could state that as long as there is no solid scientific prove about the effectiveness of breast self-examination as a method to detect breast cancer at an early stage, the method should not be recommended at a large scale. In this study it is stated that as long as there is no solid evidence it seems premature and inappropriate to have breast self-examination discouraged. There is no evidence that encouraging breast self-examination has negative consequences, for example in the sense that the method would be responsible for an increase of the anxiety level. From a health education point of view the method offers several advantages. Women can practice breast self-examination themselves, it gives them the opportunity to take responsibility for their own body and their own health. Further it is a method which costs no money and offers the possibility to practice it in a private setting. Based on these considerations it has been decided in the project to recommend breast self-examination as a method to detect breast cancer at an early stage. Finally attention is paid to the frequency and the quality breast self-examination is performed by women.

In **chapter 3** (Determinants of behavior: theoretical implications) the theoretical model of "reasoned action" of Fishbein & Ajzen (1975, 1980) is discussed. The model has especially been used in order to detect behavioral determinants. In social psychological models explaining health behavior often only so-called individual-directed variables are stressed. The theoretical model of Fishbein & Ajzen meets this deficiency as it specifically takes the social context in which people behave into account. Other advantages of the model as an instrument to explain (health)behavior are discussed in this chapter.
The main variables of the Fishbein & Ajzen model (attitude, subjective norm and behavior(al intention)) are discussed in detail, as well as the way these variables can be translated into "quantitative" terms.
Further in this chapter some characteristics, mentioned in literature, related to women's performance of breast self-examination are discussed. Based on a review of literature a number of behavioral determinants have been selected. These determinants will be discussed in further detail in answering the first question of this study. A problem in selecting this variables is that relations of this variables with the performance of breast self-examination are often ambiguous. The selection has mainly been based on the frequency these variables are mentioned in literature.

Chapter 4 describes the research methods used in this study, both for the determinants research part and the evaluation research part. That is, the methods used for the base line study and the three subsequent evaluation studies both in the experimental area (Nieuwe Waterweg Noord) and the control area (Dordrecht). The goal of these measurements is two-fold:

1. to find out how variables selected in this study are related to each other and how and in what degree they are related to information seeking behavior and practicing breast self-examination.
2. find out what the effects are of educational interventions at knowledge, attitudes and behavioral (al intentions).

The research design shows that there has been made use of a combination of panel studies and drawing new samples. The design offers the possibility to measure effects of the educational interventions, controling for possible interview effects.
In this chapter it is described how the base line study and evaluation studies were organized, how female interviewers were selected and trained and an enumeration is given of the kind of questions used in the questionnaire.
Further a description is given of the research population along the characteristics: age, marital status and socio-economic status. It is concluded that the response percentages of the base line and evaluation measurements are quite high (about 80%) according to standards of social scientific research.

Chapter 5 deals with the determinants of information seeking behavior and practicing breast self-examination. In this chapter it is analyzed which behavioral determinants play a direct or an indirect role in explaining information seeking behavior with respect to breast cancer and practicing breast self-examination among "healthy" adult women.
Based on the theoretical model of Fishbein & Ajzen and based on data from literature a selection was made of variables used for further analysis. In this chapter the results of interviews and written questionnaires among 801 women in the experimental and the control area are described. From the research data it becomes clear that:

- over 50% of the respondents indicate to know precisely how to perform breast self-examination. About 25% practice breast self-examination monthly; only 10% actually seem to know how to perform breast self-examination adequately.
- 43% of the women who never do breast self-examination indicate that they have the intention to do breast self-examination in the near future. About 25% have doubts about doing breast self-examination or not.
- attitudes towards breast self-examination and education about breast cancer are predominantly positive. Especially the partner and the general practitioners seem to play a stimulating role in this respect
- over 60% of the respondents have the intention to collect information about breast cancer. About 10% have no such intention. About 56% mention the general practitioners as the most probable source to ask for information. Only 4% of the respondents mention the district nurse in this respect.
- knowledge about symptoms, causes and epidemiological data is mediocre. Over a 55% of the respondents have misconceptions concerning the causes of breast cancer, over a 60% have a false image of the survival rates of breast cancer. At the other hand 53% of the respondents know fairly well what the incidence rates of breast cancer are.
  Women who are able to name one or two correct symptoms of breast cancer mostly are also aware of other "real" symptoms. Women who indicate "false" symptoms as correct, mostly are also wrong about other symptoms of breast cancer.
- about 75% of the respondents indicate to have a need for more information about breast cancer. Most of them (73%) name "possibilities of early detection of breast cancer" as the most important subject of interest, followed directly by "symptoms of breast cancer". No relation was found between the need for information about these subjects and present knowledge about them. No relation was found between the need for information about breast cancer and belonging to a high risk group. Apparently these women are either not aware of belonging to a high risk category or deny this fact.

In the second part of this chapter it is investigated to what extent the selected behavioral determinants explain behavioral intentions with respect to seeking information about breast cancer and doing breast self-examination. At first attention has been paid to the explanatory power of the two main variables in the Fishbein & Ajzen model: attitude and subjective norm. Subsequently it is investigated which relations exist between so-called "external variables" and these "main variables". Finally the mutual relations between "external variables" are described. The main findings are summarized briefly:

- "direct" attitudes towards breast self-examination show fair correlations with the reported performance of breast self-examination. The more positive attitudes one has the more one is inclined to do breast self-examination. Attitude and subjective norm only explain 15% of the variance in behavior (R= .39). "Only" because in other studies referred to by Fishbein & Ajzen multiple correlations vary from R= . 57 to R= .89. The direct attitude and the subjective norm towards the intention to seek information explain nearly 20 % of the variance of the intention to seek for information about breast cancer. Most variance is explained by the attitude. The subjective norm variable only adds two percent to the total explained variance.
- the correlation found between knowledge about breast self-examination and performing breast self-examination is r = . 22 ; $p < .001$. If in this correlation it is controlled for attitude and subjective norm the partial correlation is r= .17 ; $p < .001$;
- the extent to one already has knowledge about breast cancer shows no relation with the intention to seek behavior;
- younger women are more inclined to do breast self-examination than older women (r= .35 ; $p < .001$);
- no correlation was found between age and the intention to seek information behavior about breast cancer;
- although no significant correlation was found between socio-economic status and doing breast self-examination there is a tendency for women with low and high S.E.S. to be less inclined to do breast self-examination. As far as women with high socio-economic status are concerned a link is made with what Verbeek-Heida (1975) calls "the rejection of the medical model by the new fundamentalists";
- the extent to which one actively participates in social life shows a positive correlation with the intention to perform breast self-examination;
- no correlations are found between behavioral and attitudinal variables and earlier experiences with (breast)cancer;
- neither a relation between "internal locus of control" and the inclination to seek information about matters concerned with health and illness was confirmed in this study;
- as far as the mutual relations between external variables are concerned, special attention has been paid to correlations between knowlegde about breast cancer (as a dependent variable) and other external variables (as independent variables). Socio economic status and "powerful others health locus of control" are the best predictors of the extent one has knowledge about breast cancer. Women with a high S.E.S. have more knowledge about breast cancer than women with a low S.E.S. Women who more often are inclined to think that their doctor determines whether they stay healthy or not have less knowledge about breast cancer than women with a low powerful others locus of control.

With respect to the first question of this study it is concluded that attitudes are the best predictors of behavior(al intentions) related to breast cancer. This is especially true for the intention to seek information about breast cancer. As far as (the intention to perform) breast self-examination is concerned it is found that next to the attitude towards breast self-examination the variabels knowledge about breast self-examination, age and to a lesser extent "social participation" have an independent influence at behavior. According to the Fishbein & Ajzen this is not possible. From their point of view they can effect behavior only indirectly. That is, external variables will be related to behavior only through attitudes and or subjective norms.
A possible explanation of the fact that in this study external variables explain behavior directly instead of indirectly may be that not all salient beliefs related to the attitude towards breast self-examination have been taken into account. These beliefs may deal with those external variables which now influence behavior (al intentions) independently. It is concluded that more knowledge should be obtained about beliefs about breast self-examination that play a role in different age groups. More research is needed in this respect.

In **chapter 6** (Influencing determinants of breast self-examination and of seeking information about breast cancer) an overview is given of the health education interventions carried out in the project "Dealing with breast cancer". The interventions were directed to stimulating information seeking behavior and doing breast self-examination. At first some problems concerning the content and shape of the activities that played a role during the planning phase of the project are discussed. Furthermore some starting-points are formulated. An important problem related to the content of the education in this project is that women are activated to do breast self-examination monthly without a direct threat of disease (i.e. breast cancer) being present.
Additional to this problem is the fact that regular breast self-examination is not a guarantee that the disease can be prevented. Concerning the shape of the educational activities it is noticed that in general relatively few sound evaluation research have been done on effective educational methods to influence behavior. In this chapter an overview is presented of recent studies describing experiences with action-directed research in which it is tried to stimulate the performance of breast self-examination.

In this study there has been made use both of mass-media, group-sessions and individual education in order to influence knowledge, attitudes and behavior with reference to breast cancer. In describing the specific activities carried out, Kok's model (1985) of influencing behavior by education has been used. This model combines the theoretical model of Fishbein & Ajzen with two educational models; namely those of McGuire (1974) and E. Rogers (1983). In the educational intervention part of this study it is tried to influence the phases in Kok's model: attention, understanding, attitude, intention, behavior and maintenance of changed behavior.
With reference to drawing attention to breast cancer problems it is stated that breast cancer is not only a medical problem but also a societal problem. Attention to the problem should not only be drawn of the public but also of care-givers. In several ways it is tried to make the information offered as understandable as possible, not only by using understandable and readable language in written educational materials but also by clarifying as much as possible what one can do herself about the breast cancer problem.

Finally it is tried to get women to understand better what it means to have breast cancer by involving (ex)patients in the educational activities. In the attempts to influence attitudes it is tried to stress the advantages of seeking information about breast cancer and doing breast self-examination and to reduce the disadvantages as much as possible. In this chapter also attention is paid to the credibility of the communicator and the way in which this credibility is influenced by knowledge and attitudes of the communicators themselves. Next to "personal" attitudes, subjective norms may play an important role in influencing behavioral intentions. In this chapter a description is given of he ways mechanisms like social control and social support are "used" in influencing intentions through subjective norms. With reference to the last two phases in Kok's model it is indicated which attempts were made to eliminate obstacles that blockade the translation of intention to actual behavior. Further it is indicated what was done to stimulate maintenance of the changed behavior.
Finally in this chapter two sub-studies are described. In the first study it is investigated how much knowledge and which attitudes district nurses have towards breast cancer and breast self-examination. This is important to know because in this project district nurses were used as important communicators of information to the public. It is concluded in this study among 88 district nurses that although the respondents have the opinion that they absolutely have an educational role towards the public, their own knowledge about breast cancer and breast self-examination is inadequate. They should be educated well themselves before they are able to give proper education to the public. Their own expressed need for this training is high. The second sub-study, described in this chapter, concerns a study in doctor's waiting-rooms. It is investigated under which circumstances women sitting in the waiting-room of the general practitioner are prepared to read written educational materials available in the waiting room and to take these with them at home.
It is concluded from this study that women are inclined to make use of this material if it is offered in an anonymous situation. It seems that women do not want other people in their direct surrounding to know that they collect information about breast cancer.

In **chapter 7,** (Effects of the educational interventions) it is tried to find an answer to the second question posed in this study: "What is the influence of health education interventions with respect to breast cancer and breast self-examination at information seeking behavior and practicing breast self-examination?" Further it is investigated what the effects of these educational interventions are at determinants of these behaviors. The main results of this evaluation study are summarized briefly:

- the educational materials used in this project have been observed in a fair extent. Over 80% of the women who have seen the materials have also read them. In most cases the materials have been observed at the general practitioner's office.
- the main results of this evaluation materials used in this project have been observed in a fair extent. Over 80% of the women who have seen the materials have also read them. In most cases the materials have been observed at the general practitioner's office.
- nearly 2500 women participated in the 66 group meetings. Most of these meetings have been organized by women's organizations (45). At work-sites 15 meetings took place. The meetings were visited quite well and evaluated in a positive way. The latter conclusion should be made with some caution because of the high non-response rate in the evaluation study of these meetings. Over 68% of the women who visited these meetings were 45 years of age and over.

- despite the fact that the educational materials used in this project have been observed quite well, this has not led to more knowledge in the experimental group, compared with the control group. There are differences in levels of knowledge between women in the experimental group who have read educational materials and/or have visited group meetings and women in the experimental group who have not read these materials c.q. visited a meeting. However, these differences already existed before the start of the educational campaign. The campaign probably has reached especially those women who already had a relatively high level of knowledge.
- not all attitude-measurements have been repeated in the subsequent evaluation studies. It was not expected that the already very positive attitudes found at the base-line study would change in a favorable way because of the educational interventions. In order to find out whether these positive attitudes might be an artefact of the measurement methods in the base-line study, in the third evaluation study attitudes were measured at an alternative way. This does not make a clear difference in outcome: women indicate to have very positive atittudes. Of especial importance in this respect is the finding that women are convinced of the effectiveness of the recommended behavior. No differences, however, were found between women in the experimental area and in the control area. No relation was found between having read the written educational materials used in the project and the atitude towards education about breast cancer. A relation was found between the indirect attitude towards breast self-examination and having read these educational materials. However this relation is spurious, because women who have read these materials already had more positive attitudes towards breast self-examination compared to women who have not read these, before the start of the educational campaign.
- women who do not practice breast self-examination but who say they have the intention to do it indicate that the influence at their behavior of the general practitioners perceived high and still increases. After one year interventions the "percieved" influence of the gerenal practitioner increases with 9%. However, this is true for both the experimental and the control area.
- the frequency of breast self-examination does not change, neither does the quality breast self-examination is performed with. There are no clear changes in the willingness to collect information when the results of the base line study and the results of the third evaluation study are compared with each other. No differences are found with the control area in this respect. The gerenal practitioner plays an important role when one wants to get information about breast cancer. Over 85% of the respondents name him/her as the most important source of information. This finding is independent of the fact one has read educational materials or not. The district nurse plays a less important role in this respect. Women in the experimental area indicate to find it easier to get information about breast cancer and breast self-examination in comparison with women in the control area. It is concluded from this result that the absence of changes in knowledge and behavior cannot be ascribed to insufficient accessibility of the education.
- women who have read the educational materials are on the average younger than women who have not, have a higher socio-economic status and have more contacts in social life. No relations have been found between reading the educational materials and level of anxiety, health locus of control and having experiences with (breast)cancer.

- the need for educational materials about breast cancer has a latent character. Information is only then translated to action if their is a direct occasion to do so. There appears to exist a significant correlation between having read the educational materials and the expressed need for information. This need decreases among women who indicate to have read these materials.

In **chapter 8** (Discussion) the main results, discussed in more detail in the preceding chapters are summarized briefly.
As far as the usefullness of the theoretical models used in this study is concerned it is stated that it was not the goal of this study to test them at their formal validity. However the explanatory power of the main variables in the Fishbein & Ajzen model in this study is moderate.
An important question raised in this chapter is: how come that women are aware of the existence of breast self-examination, have an acceptable level of knowledge about breast cancer, have very positive attitudes towards breast cancer education and practicing breast self-examination, but do not practice breast self-examination in an adequate way?
Referring to this question first of all some theoretical notes are made. Attention is paid to social learning theory and the rewarding principle. A first explanation that is drawn from theory is that possibly the advantages of practicing breast self-examination mentioned in the educational materials are not rewarding enough to lead to behavioral change. In connection with this the content and shape of the educational interventions are discussed. As far as the explanatory power in explaining behavior is concerned it is concluded that in measuring attitudes possibly salient beliefs have been missed.
Further it is indicated that "social support", even meant in a positive way, not always needs to have a positive effect at behavior. Next to theoretical notes some methodological notes are made concerning problems of attitude measurement and the problem of social desirability.
At the end of the chapter recommendations are made for further research. Recommendations are also given with respect to the content and shape of futural educational interventions.

Finally it is concluded that the body of knowledge on how to influence behavior regarding breast cancer by educational interventions is still poor. Education about breast cancer and breast self-examination therefore still has to be developed at a rather intuitive way. There are to few empirical research data that can indicate precisely what the content of the education should be, which target groups should be reached in particular and by which methods.
In general it is stated however that health education programs should be constructed in such a way that general goals and specific objectives, interventions and evaluation criteria are consistent with the theoretical base used in this programs. Most health education programs lack this consistency and as a consequence, results of studies, even if the outcomes are favorable, are difficult to explain in terms of ways of how they influence cognitions, change behavior or both.